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ABSTRACT

Intended for people interested in replicating the ideas contained in this manual in their own communities, the handbook describes the Family Exchange Center (FEC), an approach designed to support families with developmentally disabled children. Services offered include social, recreational, educational, mutual aid, support, and respite activities. A rationale for the FEC concept is given in which the family is considered as a system and in which reactions of the system to identification of disability in the child are discussed. Changes in parent/professional patterns and the issue of trust and confidentiality in the FEC model are examined. An organizational chart illustrates the component parts of the FEC, including the coordinating committee, monthly organizational meetings, and a variety of family activities, including informal parent networking, play and discussion opportunities for siblings, and advocacy groups. A final section on administrative considerations addresses staffing and outreach to professionals and consumers. (CL)

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Empowering Parents of Disabled Children:

A Family Exchange Center

by Judith Simon Bloch, ACSW
Martin Seitz, ACSW

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Empowering Parents of Disabled Children: A Family Exchange Center

by Judith Simon Bloch, ACSW
Martin Seitz, ACSW

This handbook describes the *"Family Exchange Center" (FEC), which offers a nontraditional approach to helping families with developmentally disabled children. It designs a system of support different from conventional professional offerings because it views parents as participants rather than as patients or clients. It is based upon an assumption that such parents are best able to identify and articulate their own needs and should share responsibility with professionals for developing and providing services to meet these needs.

The authors have written a technical assistance manual for a wide and varied audience to be adapted for their specific use. It is for special education schools, parent organizations, Y's, churches, synagogues and service clubs; in short, for any and all professionals and organizations with an interest in providing a community support program for families of the developmentally disabled.

*This program was supported with grants from the New York State Developmental Disabilities Planning Council through the Federal Developmental Disabilities Assistance and Bill of Rights as amended by P.L. 97-35 and United Way of Long Island.

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I. Acknowledgements

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Finally we want to thank all of the families we have come to know over the years. We think that they have taught us what we have needed to learn about working as partners together.

II. Preface

When Congress passed a law in 1975* and mandated a free education for all handicapped children, public policy throughout the United States underwent a dramatic change. Today disabled children are no longer institutionalized but instead remain at home and attend schools with special education classes. Many are identified earlier and some states offer infant stimulation, toddler and nursery programs as well. While this community based care is for the most part giving these children the education they need, it has made the problems of their families even more acute.

At Variety Pre-Schooler's Workshop, a preschool special education program, we saw that families needed something the system was not providing. This handbook reflects the rationale and program we developed to respond to this problem. We found that if we were to reverse dysfunctional family behavior patterns we had to change and reorganize our professional service delivery model.

With rare exceptions, children with disabilities are born into families who have neither the knowledge, support systems nor skills to deal with their child's special needs. Yet the plight of the parents directly affects the outcome for the handicapped child. The chronic worry and stress families experience because of their disabled child's troubled development places the family at risk. Unprepared for the unique burdens of rearing a handicapped child, even strong, intact families may become disorganized and chaotic.

Since the needs of the disabled child are so pressing, the pain of the parents, siblings and grandparents is often overlooked or inadvertently ignored. But all these family members must learn to cope with their emotional reactions to their changed circumstance if they are to become a useful resource to each other and a help to the disabled child.

Despite this gloomy picture of family life, most family members do not typically consider themselves patients or clients. Traditionally, they do not seek out or utilize psychotherapy for themselves. Indeed some mental health agencies have alienated parents because they automatically assumed they should be patients.

*P.L. 94-142

As a rule, parents are also unable to benefit from or use the usual sources of informal advice available from friends, family and the popular press. In addition, they are often deprived of access to local adult education programs or social and recreational activities and the ordinary community supports readily available to families with healthy children.

It was the result of these observations and what we learned from our families that compelled us to move toward the creation of a new model of service. We do not think, however, that the approach we came to is unique to our setting. Quite the contrary, this approach is compatible with other host agencies ready to build programs on the following assumptions:

- Families with disabled children are like all families. They differ greatly in their personal adjustment, functioning and nurturing capabilities.
- While family interactions may not have produced the child's pathology, they can influence outcome.
- Periodic parental confusion and overwhelming anxiety are normal reactions to a real crisis.
- Family dysfunction is often a reaction to complicated, inordinate childcare burdens and chronic stress.
- Parents are the most indispensable and least replaceable family program planners.

III. Introduction to The Handbook

This handbook introduces the FAMILY EXCHANGE CENTER (FEC), a program in support of families with developmentally disabled children. It is designed to establish a system of support different from conventional professional offerings because it views parents as participants rather than as patients or clients. This model assumes that consumers are best able to identify and articulate their own needs and should share responsibility with professionals for developing and providing services to meet these needs.

The family of the child is its major resource. It is the social system with ongoing responsibility for the child's care, protection and socialization. Families with developmentally disabled children need a community support system in order to fulfill their vital function. When this is not available and when the family "fails," the child suffers irreparable damage and the community is often compelled to provide costly and inadequate substitute care. In order to prevent the disintegration of family life, to assist parents to effectively rear their children, to promote the full development of all the children, the community needs to provide adequate social supports as well as normalizing experiences.

A. *What is a Family Exchange Center (FEC)?*

A Family Exchange Center (FEC) is a system of professional and peer support. An FEC offers social, recreational, educational, mutual aid, support and respite activities to families of the developmentally disabled. An FEC offers not only a program but also a place with at least one clearly designated and reserved clubroom or lounge which is regularly available and can adequately accommodate a few or a group, with or without children, both formally and informally.

Each FEC should have in common a basic rationale. While the place, the program, and the activities may differ from setting to setting we need however to hold to one constant, the approach. In each instance the new gestalt recognizes:

- The primacy of the family
- The new presence of children with disabilities living at home
- The value of an interfamily mutual-aid network
- The value of a system of linked and integrated professional and parent services with responsibility carried by both

B. *What does an FEC do for families?*

An FEC provides a place that supports family life and offers opportunities for friendship, recreation, and natural respite. Solace and practical advice are provided by parents for each other. They are comforted by the recognition that they are not alone; that their situation and fears are similar to those of others. Parents become confidants, form mutual-aid networks, and often assume the role of a caring extended family.

The Family Exchange Center is a partnership between professionals and families and a family-to-family support system. In this way it provides a community model that integrates and balances the needs of the children in relation to the family, and the family in relation to the community. The FEC responds to the parents' need for relief from stress while addressing the needs of all family members for support, information and recreation. It creates a primary preventive practice model. It links and coordinates various social and emotional supports to families. What emerges is a new gestalt.

C. *What does an FEC do for communities?*

An FEC provides a cost-effective primary prevention program. It prevents later family problems, empowers parents, and initiates mutual-aid networks. It creates a balance between family self-reliance and community resources.

D. *Who is this handbook for?*

This handbook is written for providers, consumers and host agencies interested in establishing a Family Exchange Center in their own communities. It draws upon the experience of a particular type of agency—a school, from which suggestions and ideas have emerged. It is a technical assistance manual but not a cookbook with a collection of recipes. It is meant for parent organizations, special education schools (both public and private), Y's, churches, synagogues and service clubs; in short, for any and all individuals or organizations with an interest in families with a disabled child who are receptive to the need for a community support program. It simplifies the task of establishing an FEC because it presents a framework and includes information about the following:

- A philosophical approach
- Implementation activities
- Program modules
- Potential pitfalls
- Suggested solutions to problems
- Staffing

E. *How to use this handbook*

This handbook will serve as a practical guide to any group planning to replicate a Family Exchange Center. The various parts or models of the FEC are described. Each module is a building block in a support system to families. Each FEC should suit the needs of its own families, its own capacities, its host, and its own community. Our own FEC is described. *However, one FEC is not a carbon copy of another.*

F. *Something for everyone in the family*

Too often the disabled child is the only one whose needs have been considered in planning programs. However, it is now increasingly recognized that all members of the family need to adapt to changed circumstances which accompany the presence of this child.

The FEC provides opportunities for family members to help one another, to spend time together, to have fun, and simply to enjoy one another's company. Through spectator and participant activities a family can experience the natural "respite" that most other families take for granted.

In addition to these family activities, the Center offers support groups for parts of the family. This allows individuals to develop their own resources and enjoy activities away from the complete unit. Mothers, fathers, siblings, grandparents—all have shattered dreams, persistent worries, and troublesome fears. Each needs a place to identify, explore and deal with these concerns. Children may need to separately pursue and develop their own interests and talents.

IV. Rationale: Professional Issues

A. *Variety Pre-Schooler's Workshop: History*

PSW* began in 1966. It is a pioneer program, one of the first, to provide a school for the early identification, evaluation and education of preschoolers with learning, language and behavior problems. From its inception, it has sought to offer services to their parents as well. Since that time, it has grown to include not only a school for disabled children and related services to their families, but also support services to other families in the community.

Hence the idea for the FEC. Because of our increased awareness of the importance of the role of the family, our services could not remain focused only on the educational needs of the disabled child. The needs of their families could not be ignored. The two could not be separated. We could not forget that in the past, handicapped children were often removed from their homes, not only because they were disabled, not only because there were no schools for them, but also because their families could not surmount the series of crises their presence created. This realization obliged us to find a way to address this family issue and led to the development of a comprehensive model with interrelated activities which supports the child's primary resource, his own family. Parental utilization and evaluation of these services helped shape our approach to the family and the program offerings.

B. *The family as a system*

It is important to remember that the disabled child (often referred to in the mental health circles as the identified patient) is part of the family system. Intervention efforts with the child are more effective when they reflect an understanding of the family's stage in the life cycle, their patterns of interaction and their needs and values. Within this framework consideration is given to their assets, emotional and financial, and especially those strengths that can be called upon to bolster parenting competencies.

Planning for parenthood and the birth of a child are major milestones in the life of adults. The wish to become a parent is prompted by a variety of needs and expectations, among which is the desire to expand one's circle of loved ones—to love and be loved. For some it is perceived as a basic fulfillment of marriage. Parenthood is chosen for many different reasons, but the hope is always that this will be a time of emotional enhancement. With conception and parenthood come aspirations for the family, dreams of love, security and achievement. The plan is for a healthy, happy child. The expectation is that the child will be an asset, although the specific form of this fulfillment depends on individual parental needs and fantasies. For many this is a critical way to meet their needs for purpose and responsibility. Some see parenthood as another opportunity to satisfy their own unfulfilled childhood needs or to realize thwarted adult ambitions. Still others may hope that parenthood will be a means of providing protection and care for themselves in their old age. Most of us expect that our children will do at least as well as we did in life, or better.

Because of these fundamental and deep-seated yearnings, families do not move with tranquility from one with well children to one which includes a developmentally disabled child. A thwarted dream is not easily abandoned. The first crisis is the identification and placement of a child with a hidden developmental disability. This constitutes a major trauma because it alters the normative family development stage and parenting task.

*Name changed to Variety Pre-Schooler's Workshop in April 1983.

Instead of celebrating their toddler's milestones, parents are compelled to make decisions about evaluation and remediation. Primary parental hopes and fantasies are threatened with this acknowledgement of a child's impairment. Parental denial may serve to protect the family's self-esteem and image, while professional confirmation of pathology in a child poses a challenge to those dreams.

This stage of first identification of a disabled child requires significant adaptive changes. If we remain mindful of the many reasons couples choose parenthood we will be better prepared to deal with initial and critical parent/professional encounters and take better advantage of this opportunity to open lines of communication and trust. Increased professional sensitivity will prevent us from alienating parents or undermining their confidence, and set the stage for the long-term alliance that we must form in order to promote and protect family strength and enhance the disabled child's development.

The literature in the field indicates that the incidence of divorce, separation, child abuse and alcoholism is much more prevalent in families with handicapped children. Time alone does not necessarily ease the pain and disappointment an entire family experiences when they live with a disabled child. Worry and the extraordinary burdens of childcare often erode family strength. We have seen families become isolated and life's pleasures muted. There remains little time or energy for social activities. Boundaries that permit necessary subsystems to work are not maintained well. The marital dyad in these instances becomes weak and joyless. Family life becomes problematic and unsatisfying. Chronic stress and worry combine to create patterns which contribute to pathological or marginal functioning, and in many cases families are destroyed.

We know too well that sometimes the family system does not function in a way that meets the needs of all its members. We have seen mothers submerge themselves in childrearing, and know how their self-esteem is undermined by their inability to help their child change or improve his/her behavior. We have heard mothers struggling with their natural feelings of irritation and disappointment, berating themselves when they could not reconcile those feelings with their own expectations that they should always and only love their child. Sometimes fathers become totally consumed with their financial responsibility for providing. They become disengaged from parenting and resentful of their wife's preoccupation with their disabled child. Grandparents have also to deal with their altered expectations for the grandchild. In addition to the feelings of loss and disappointment, they are probably less able to give help and advice because of the special nature of child-rearing required with which they are unfamiliar.

Siblings, along with parents, must cope with new demands and disappointments if they are to develop their own potential and also become resources for each other, and of help to the disabled child. Siblings preoccupied with the seemingly "unfair" distribution of parental concern may simultaneously understand, resent, and feel ashamed of their "unacceptable" reactions. They need to learn to deal with these personal dilemmas. A better understanding will permit them to develop their own identity and improve their relationship to their disabled sibling.

The nature of relationships within the nuclear and extended family identifies sources of help or difficulties. Parental concerns about their disabled child are shaped by considerations such as age, physical stigmata, appearance, diagno-

sis, and current level of functioning. Despite this child's extraordinary needs for care, parents must still remember to look at the needs of the entire family.

Parents need information in order to be better prepared to deal with the predictable and periodic issues which call for good decisions. They have to acquire the skills, attitudes and strengths that will help them sustain their families. Our agency needed to find a way to respond to this issue. For all these reasons we developed a support system for the family which became the FEC.

C. *Another approach to families*

For reasons that we already described, maladaptive family patterns repeatedly emerged. We wanted to help by entering these family systems but we recognized that we had no such understanding or "contract" with these families. Parents came seeking a good preschool education for their child, but most did not perceive of themselves as clients. In fact, even when they were experiencing problems many parents were angered and complained they were demeaned when it was assumed they were clients. This approach was seen as patronizing. If we assumed that a family had to choose client status in order for us to provide service we would have helped only a few. Since we had already learned that direct suggestions recommending therapy (even to the many-troubled families we knew) were often disregarded or responded to with distress, another approach had to be found. Therefore, we chose to remain sensitive both to their needs and to their rights, to decide whether or not their family or they were clients. Furthermore we found that some parents, in fact, did not need to choose client status for something of value to happen.

Given this understanding we realized there were a number of ways we could address this problem of family need without alienating parents that would also provide an entry point to the family system. We found we could engage more parents with a different approach. We could promote family life education and at the same time reduce the stressful social conditions which strain family functioning. We could also promote activities to enhance their caregiving skills and their effects by creating opportunities for informal family interchanges in social situations.

With these concerns in mind we created another gestalt, the FEC, to supplement the school's family counseling and social work department and to provide networking alternatives. Programs that parallel social, recreational, educational and respite activities as they occur among non-disabled families were established. The staff plays a crucial role in this system. They are responsible for initiating contact with parents and for motivating them to select and participate appropriately. In this way two of the child's major support systems, home and school, are linked. These new opportunities include membership and leadership in the FEC. Parents are not assumed to be either interlopers or clients, but rather approached as partners in the education and socialization of the disabled child.

Childrearing issues are viewed as problems to be identified and resolved jointly by parents and professionals. In this model consumers are encouraged to participate and to define for themselves and clarify with their families their own needs, roles and responsibilities. With time parents have formed mutual-aid networks, and often assumed the role of a caring extended family.

There are other dividends in this approach:

- For many parents it seems clear that opportunities to provide for others strengthened and enhanced their own skills. We saw that the shift from an intra-family preoccupation to an inter-family interest (with concern for others like themselves) was of personal value in restoring and maintaining emotional balance.
- The expanded dialogue between the professional staff and the parents afforded by the FEC creates new entry points into the family system. This increased utilization of additional professional services, such as counseling.

D. *Changed parent/professional patterns*

Increased interaction among families and staff provides more opportunities to expand and enhance the nature and quality of supportive exchanges. It also introduces the potential for problematic exchanges, and highlights issues of power and control. It exposes "fallibility." Flaws or limitations in parenting or professional competence or in the service delivery system are easier to observe and more likely to be noted. Some professionals see this as a good reason to maintain the status quo. They argue that heightened intimacies and parental involvement in program planning will lead only to stressful conflict between parents and providers and to increased difficulties in establishing and maintaining productive client relationships. They also contend that this increased interaction dilutes parental anxiety, and diminishes their perceived need for professional services.

So we can see that despite the general philosophical professional accord regarding the value of parent involvement, there are also legitimate reasons to challenge this new model and understandable professional hesitations regarding its proper place. Another factor contributing to the professional reluctance to adopt it relates to shared planning responsibilities and the conflicts this may generate. Some assume that conflict is an unacceptable state of affairs and suggest that all strong differences of opinion, especially between consumers and providers, are to be avoided. We believe differently. It is better to create an environment where disagreements are to be expected and accepted. What is important is that there is an established structure for conflict resolution.

We have made a strenuous effort not to create any unnecessary conflict between the functions of the new structure and the legitimate traditional functions of the family counseling department. We have tried to be watchful lest we substitute something just as undesirable as the "old resistance" by professionals to parent involvement in program planning and parent-to-parent networking. In the "old resistance" the view was that parents needed to be directed and controlled by the professional for their own best interests. Parents could not be trusted to interact with one another alone. Without the professional presence, great harm could be done as parents might behave inappropriately, supply each other with wrong information and even "hurt" one another. We have now seen the emergence of a "new resistance" to the changing role of the parents. In this form of reaction, professionals have responded to burgeoning self-help movements with "self-exclusion." Some may be unrealistically viewing these new movements as magical, with power to achieve every-

thing without the professional, and maybe even because of the absence of the professional. Indeed, some of our school professional staff seem to have initially believed that such was the philosophy underlying the new structure.

Actually, we have recognized with them that we must not substitute the "new resistance" for the "old resistance." The challenge for us is to find the means for better integrating the work of the professional and the families who are the consumers of service.

Despite these complications we have found that once our own school staff was convinced that expanded family support services were vital they encouraged parents to participate in the new FEC program. Despite the supposed threat to their own professionalism, staff saw that the problems which emerged with this increased parental utilization could be resolved, and were overshadowed by the gains to these very same families.

E. *Confidentiality*

The issue of trust is probably the most significant affective issue in relationships between consumers and providers. Respect for the dignity and privacy of the family is an essential ethical consideration, as well as a strategic practice matter. Bonds of trust are built on the way in which confidentiality is managed. Fears that ideas and feelings expressed in confidence will be used later against those who risked self-disclosure must be put to rest. Guarantees about insuring confidentiality cannot be made glibly in a school where staff need to share information unless certain precautions are taken and certain practice principles are followed.

The FEC introduced still further complications. Its structure creates a model in which parents as participating members are more formally involved in the confidentiality issue. Both staff and participants must be bound by basic principles of confidentiality. This presumes that all personal material is to be handled respectfully—never in a casual or careless manner. Since integration of services is critical, information needs to be shared with those whose role in planning requires this. Staff cannot withhold pertinent data. While this principle entails some risks, the alternative is even more problematic. It undermines the "team" concept and our premise that interrelated and planned services produce better work. As a result, staff will sometimes need to "earn" trust. But one does not do private practice in this system.

All consumers must be informed of these ground rules—in advance, children as well as adults. Periodically, there is a temptation to share information from the group with outsiders. Principles about sharing information by family members about other family members are influenced by position and age.

For example, activities for children, to be described later, are important parts of the FEC. In this regard, the establishment of trust between an activity leader and the children is a basic and primary requisite. It has to be developed in order to allow the group members to begin to work together. The children need to know that the expression of their ideas and feelings will not be used against them. In these groups, this issue is complicated because guarantees about confidentiality as they ordinarily operate have to be modified.

The children's ages and the nature of the work are the main reasons that the traditional professional assurances regarding confidentiality cannot be made. To give young children too much independent control and power, in view of their dependent position in their families, is unrealistic and will prove to be unproductive in the long run. Instead, trust has to be achieved through skillful work with the group and clearly expressed attitudes on the part of the leader. The group experience has to produce continuing evidence that the leader is attuned to family relationships and interactions, and is caring and protective of the children's perspective. The children have to understand that any sharing of information with their parents will not hurt them, but could be helpful.

It is clear that we choose to maintain a family intergenerational perspective because we know that sibling dynamics are fundamentally related to the larger family context. We cannot exclude their parents. But the children in the groups, especially in the well sibling groups, need to know that they will be involved in any decisions to share information. They need to know this will be done to help them communicate more openly with their parents, to share their reactions to stressful family incidents, or to sensitize their parents to their problems and pain.

Clearly all important relationship issues cannot be addressed in any one group. As a result we found our family approach has two advantages: it is more likely to enable a staff member to engage parents as allies and it is also designed to better use children's groups to gain entree to the family system if further counseling work becomes necessary.

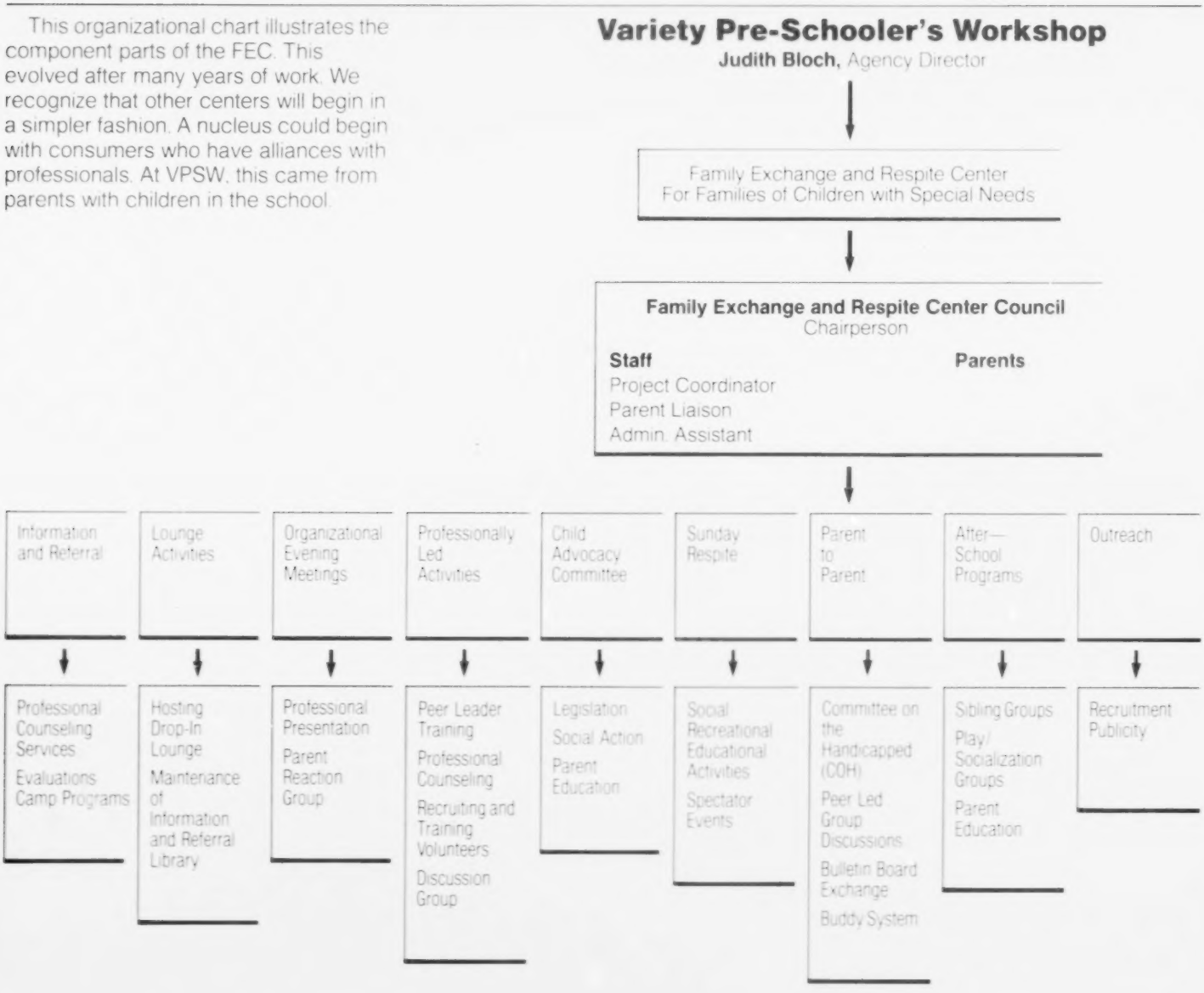
With regard to our adult consumers, our parents, we find that they interact in many ways in this FEC model; sometimes they are participants in professionally led groups and at the same time friends in social or recreational activities. Much more sharing of personal and private information is likely. There is also more interfamily interactions and more personal behaviors are observed. As more family members are involved and as groups include greater numbers of people, the likelihood of a violation of confidence is increased, e.g. a man who shares information he heard in his support group with his own wife has broken a confidence. The wife may herself be a member of a mothers' group and on close terms with the woman discussed. Children in a sibling group may inadvertently share other people's "secrets."

It can be seen that this system poses hazards to confidentiality. Problems can develop that also may interfere with the sharing, planning, and coordinating necessary for good programming. The more interchange among adults in these associations, the more the likelihood of "slips" or gossip. Professional staff may sometimes withhold information which should be shared because of these fears. These problems must be appreciated by all participants since violations may occur in any of the groups, i.e. fundraising, advocacy and counseling. There is no simple solution.

We need to be most explicit about the confidentiality ethic and norm. We need to introduce and reinforce it regularly and point out that violations carry a great potential for harm. We can also reassure ourselves with the knowledge that good experiences will build credit and if violations occur we can work with them constructively, and not look only to blame.

V. The Family Exchange Center (FEC)

This organizational chart illustrates the component parts of the FEC. This evolved after many years of work. We recognize that other centers will begin in a simpler fashion. A nucleus could begin with consumers who have alliances with professionals. At VPSW, this came from parents with children in the school.



A. *The Coordinating Committee*

At the heart of the FEC is a Coordinating Committee. It carries a number of responsibilities for the FEC but its basic charge is to help the FEC realize its own stated purpose or mission. In other words, its major task is to provide a program in support of families with developmentally disabled children through a system of professional and peer supports. In order to achieve this primary objective the Coordinating Committee, a group of professionals and parents of disabled children, will determine policies and formulate and approve their own plans, or those developed by the director or their own committees. If the decision to hire a director is made, that person in turn would be responsible for selecting and supervising subordinate staff, but would also be responsible to the Coordinating Committee for his/her own performance. While the Coordinating Committee might or might not do its own fundraising, it would need to understand their fiscal capabilities and constraints.

A Coordinating Committee requires a special membership mix in order to achieve its purpose: a group of consumers and professionals with a varied frame of reference. In theory, this combination of interests, values, knowledge, professional training and skills should unite competent people, enable them to problem solve more effectively and produce a more significant and socially useful program. In reality the exact opposite has often been described when consumers and professionals share responsibility for decision making. Doubtful or dependent parents may underestimate contributions from their own quarters and contribute to the creation of a hierarchy in which the professional is the primary or only decision maker. While this tendency can have some functional purpose in the early life of the FEC and the Coordinating Committee, it is of questionable value if it persists. If the professionals initiate the FEC they do indeed carry responsibility for introducing structure and programs. Any initial parental tendency to rely on professional experience and resource should serve to strengthen and build the group. However, it should not interfere with increased parental responsibility or interactions necessary to solidify the identity of this group and further its substantive work.

"Territoriality" or a limited and rigid characterization of professional responsibilities and behaviors can also interfere with necessary collaboration. Parental mistrust of professionals and the need for some compromise of autonomy may heighten issues of "power and control." The tendency to identify and maintain a separate and unique position based on one's professional or parent perspective can interfere with the need to tolerate the ambiguity and overlays in function that will emerge and that must be accepted if a new synthesis is to be reached.

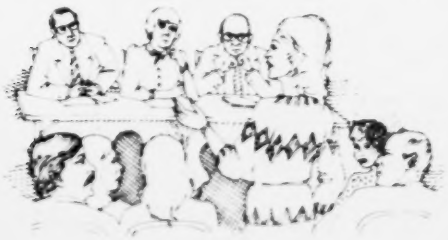
The group's success in dealing with personal characteristics that tend to polarize and its ability to compromise will not only enable them to produce a unique and more effective constellation but also serve as a role model for other professional and parent coalitions in the FEC modules which will of necessity struggle with this same issue.

In addition to the "internal" group issue which can produce conflict and tension there are potential problems in the Coordinating Committee's relationship "externally" with its host agency. Even though the FEC goals and those of the host agency seem clearly compatible, differences regarding policy or practices may emerge. The Coordinating Committee may sometimes face a middle management "dilemma" and carry responsi-

bility for creating a delicate balance: responsible for FEC program development and to its own FEC members, and accountable as well to their host agency. As a result the Committee needs to be sensitive to obligations and constraints from both sides. For all these reasons, the selection of membership on this committee is crucial to the success of the undertaking. The willingness of the members to listen to each other; their personal flexibility and their tolerance for the tension and anxiety inherent in this structure will be critical. Its participants will need great conviction regarding the value of this new parent/professional synthesis if they are to make it work.

B. *Organizational meetings*

A monthly organizational meeting is the key program module because it serves to introduce and restate the FEC mission. Its philosophy of a service grounded in consumer participation with democracy in action becomes clear at this time. It



provides good opportunity for recruitment of new members, and serves as a seeding ground to fertilize other program modules. Most important, it conveys a sense of organization belonging, and can stimulate members by creating a sense of mission and accomplishment.

Our early meetings were almost always smaller in attendance than hoped for or expected. Despite our conviction that there was great need for the organizational meetings we were continually surprised by the great amount of outreach it took on the part of the Coordinating Committee members to encourage people to attend regularly. We found too, that much thought needed to be given to the objectives and accompanying planning for each meeting. We came to realize that members and potential members were much more comfortable if there was a consistent format to the meetings. Anxiety diminished as people knew what to expect.

The format of the meeting which finally evolved is simple but effective. It symbolizes again the notion of partnership between parent and professional. In the beginning part of the meeting refreshments are served and Coordinating Committee members actively seek out old members and welcome new members in a relaxed and informal manner. The formal part of the program begins with a brief introductory statement about the goals of the FEC and a brief report of its activities by a parent member of the Coordinating Committee. This is followed by a presentation in depth on some topic of interest, by a "team" of professional and parent. Usually, a parent reactor shared personal experiences and reactions to the topic presented by the professional. The balance of the evening is taken up by small group discussions (for parents only) in which there is a focus on the affective issues evoked by the topic.

Alerts

We found that everyone involved in this organizational meeting needed to be clear about its purpose and plans. We prepared, anticipated and coordinated by thinking through some important ideas. For example, the "experts," usually represented by one professional discipline or another, need to understand that their audience might have ambivalent feelings toward them and what they might have to say. If the "presenter" is a mental health professional, it is likely that the family has been reluctant to seek help from that source because of a perceived loss of self-esteem or fear of classification as a patient or client. If the presenter is a physician, or educator, it is likely that some past experiences with such professionals may or may not have been satisfactory. Such awareness prepares the "presenters" for "testing behavior" and helps create an accepting and empathic response to audience reactions and serves to diminish negative feelings. If the presentations are information-giving they have to avoid the

condescension professionals are prone to with lay people, if they are to be well received.

Parent reactors, for their part, need to be chosen for their ability to "stay with the theme" and to share from a more personal view so that other parents can identify with them. The trained parent leaders need to learn to have faith in their leadership skills and in the value and importance of their roles in facilitating a discussion in the small groups. Peer leaders with status have a special kind of credibility; as a result they can enable other parents to come into greater touch with their own feelings and to experience the emotional support which comes from sharing.

Coordinating Committee members need to involve themselves in all aspects of the Organization Meeting, much beyond the planning function. They need to be active in welcoming, outreach, and linking parents to one another. Most important, they should be active in informally soliciting feedback, and alert to problem areas and reactions by parents which need followup, offering encouragement and personal counsel where needed.

C. *A variety of family activities*

As is pointed out continually throughout this handbook, the raison d'etre for the FEC is to provide opportunities for families to help families. The modules to be described now increase opportunities for families to interact with each other, exchange information, make choices of program activities, participate in recreation, obtain respite, and engage in forms of individual and collective actions to advocate for their concerns. The relationship between the professional and the family is a non-traditional egalitarian one, and the thrust of the design is to establish a real partnership between family and professional.

1. *Parent to parent*

All of the modules increase opportunities for interaction among families to enhance living, diminish loneliness, and to gain skills in coping which come from sharing in common problems. Social linkages and supports therefore appear naturally for families experiencing a common fate. However, there are certain aspects of structure which if included will reinforce and expand the informal networking which occurs, namely, social lounge activities, information and referral, and a telephone help line. We think that there is a logical sequence to these particular activities. All of them grow out of the organizational meetings already described. It is relatively easy to interest parents, mothers in particular, to plan and decorate a room set aside for a lounge, and to form a hospitality committee to welcome new families and to assist in social networking. The lounge also becomes the logical location to place written information, pamphlets, bulletins, news stories. It is in this way that very important information and referral services begin to be offered by knowledgeable and experienced families to others. Somewhat later, some parents may even choose to move beyond their own immediate concerns and serve the wider community by providing a telephone help line to other worried families.

Alerts

It is apparent that parents who take such leadership responsibilities often have attitudes and personal qualities which uniquely equip them to help other families. They are frequently seen by other families as allies and people who can be identified with and trusted. They can acquire or enhance their talent and

skill in imparting information and facilitating discussion in groups, and in work with individuals and other families, with professional consult when necessary.

It is possible, however, that some parents may not be suitable for such assignments. In a sponsoring organization such as our own, which has a strong professional base, the staff has taken responsibility for screening parent leaders, training them, and offering ongoing consultation to them. Where the sponsoring organization is made up exclusively of families themselves, naturally the overall design of the FEC will differ in many respects from our own blueprint. In such instances, we think it might be prudent for the organization to enlist professional consultation for screening and leadership training purposes.

2. *Respite and recreation*

It can be disconcerting for some traditional educators or mental health professionals to visit the building on Wednesday afternoons, some evenings, and some Sundays, the times that the FEC is most visible. Excluding staff and volunteers there may be upwards of 150 people, taking part in a variety of activities. Groups for siblings, groups for fathers, groups for mothers, informal lounge groups, groups for the developmentally disabled may be meeting. There may also be times when a political action committee of parents which has also taken on a "watch dog" function is meeting. It may also be an afternoon when there is a regularly scheduled Coordinating Committee meeting. At these times, it doesn't look like the ordinary school or the typical social agency. What comes to mind is the ambience of the old Settlement House. More specifically, key aspects are described as follows:

2a. *For the developmentally disabled*

Activities are planned which benefit the child's social and cognitive development and provide opportunities for fun. These activities need to be developed so that a child does not experience them as "further schooling."

Children are placed in small groups of five or six with a supervising adult leader and two school volunteers. Activities involve a mixture of arts and crafts, gym activities, music, and outdoor play. Projects undertaken are not elaborate, are appropriately varied, and designed to cultivate a climate of friendliness and satisfaction among the children.

2b. *For siblings*

Along with activities for the disabled children, the FEC provides opportunities for play and discussion for the siblings. These groups are designed to give these youngsters the opportunity to learn that they are not alone; ventilation, problem-solving and camaraderie are the goals of such groups.

2c. *For parents*

While the children are occupied with recreational activities their parents are given options. They can leave the building and return later to pick up the children. They can relax too by remaining in the building, having coffee and chatting with other parents in the lounge area. Parents also have the choice of participating in a more formal program. Sometimes, there are parent education meetings, and guest speakers are invited to talk about such topics as legal rights, religious training, child development, etc.

2d. *For the entire family*

The Sunday program, more than the afterschool program, was especially designed to provide a four-hour afternoon of social and recreational activities for all members of the family. At such a time, one might see a father-son softball game, mini olympics, or some spectator activities for the entire family involving films, folksinging, or circus-like events.

In addition to these mass events, it is possible to select opportunities to combine groups of disabled and well children. Mainstreaming the developmentally disabled child and well sibling has proven workable.

Siblings thus have a further opportunity to experience empathy, particularly when they are placed with disabled children who are *not* their siblings. The mixed groupings gives all of the children the experience of realizing that their family is not unique and that activities together can be pleasurable.

Alerts

Childcare is a vital component of the recreational and respite activities. Parents must believe that their children, whether well siblings or developmentally disabled, are in competent caring hands and in a safe and pleasant environment. Two essentials are: adequate coverage and a well prepared staff. One-way mirrors and intercoms (if possible) provide opportunities for direct observation and reassurance without interrupting activities.

Staff are professionally prepared for their work, but many of the activities require a one on one ratio of children to adults, so that staffing must include a very significant number of volunteers. Volunteers provide the extra coverage and an opportunity for increased individual attention and affective experiences which prove both satisfying to the child and volunteer.

It is apparent that some thought must be given to questions of recruitment, screening and training of volunteers. Our own experience has been very successful, as we have recruited volunteers from local service clubs, retired persons, civic organizations, and high school and college students.

3. *Parent education*

Parenting is perhaps the most important undertaking in the life of any adult but the one for which we are least prepared. On the job training seems to be the way many of us learn how to parent. Along the way there are some who can serve as role models and teachers, but for parents of the disabled these people are hard to find. Too few in their circle may have comparable experience. As a result parents of the developmentally disabled child find that the collective wisdom of grandparents, relatives, friends and community offerings of parent education are generally not useful. These are usually geared to the parenting of "normal" children.

The FEC changes that pattern. It provides parents of the disabled with natural opportunities to meet and learn from each other. Parental expertise in matters

pertaining to their own child is a given. This basic assumption enhances a sometimes diminished sense of self-esteem. It helps parents learn to trust themselves. However, the Center is not just a place to get information but a place to learn how to put that information to use in practical and valuable ways.

Parent education at the FEC takes place in both a formal and informal manner. Specific programs and series are planned and presented at our large "open" membership organizational meetings and small "closed" seminars. Topics reflect themes identified by the parents as issues of concern. Speakers are selected who are sensitive, knowledgeable and willing to recognize the value of parental experience.

A seminar series allows time for an in depth look at a problem. It provides a valuable workshop in which the parent can more thoughtfully and slowly ask questions, share experiences and problem solve. Sometimes the presenters are "experts" drawn from the professional community and at other times the presenters are parents themselves.

Alerts

The key to the success of any education series is the need to be sensitive to the important concerns of the "target group." To this end, the Coordinating Committee, comprising parents and professionals, has made considerable efforts to be close to the needs of the overall membership. Parent leaders have used the informal social network to gauge the reactions to certain educational programs. From time to time, needs assessment questionnaires have been employed to keep topics and programs timely and relevant.

We think too, that it is necessary to be clear about the function of parent education within an FEC. It is designed to provide information and skill training to parents but *not* to become some vague experiment in "group psychotherapy." We think it is important to maintain clarity about this, because topics are so emotionally laden that parents might (out of need and pain) share intimacies and regret this afterwards. We have found that we can prevent premature or inappropriate self-disclosure by stressing similarities among parents and reinforcing the cognitive aspects of the issue. Individualizing and counseling of parental concerns needs to be done separately and privately and is not the function of the parent education module.

4. *Advocacy groups*

Some parents choose to translate their concerns about raising a disabled child into action. That action can be channeled to serve not only their own children but all handicapped children. Membership on an advocacy committee can focus that energy.

The Advocacy Committee of the FEC has served a variety of purposes. The group has assumed responsibility for sensitizing the local community to the presence of the developmentally disabled through speaker engagements, appearances on local radio and TV stations, and articles in the press, etc. The advocacy group has also served as a resource to parents as they have needed to learn better how to negotiate with their local school districts. It has also served as a "watchdog" committee to monitor legislative issues and to alert families and professionals to proposed legislation that could affect the delivery of services. Members have attended local, state and federal hearings on issues of concern and reported back to the FEC.

Alerts

The setting of goals and activities of the advocacy group needs to be realistically monitored by the sponsoring organization. If the group intends to follow a path of activism, there are some thorny issues. The political climate in which the FEC exists can be a limiting factor. Where does the organization get its funding? Will an activist advocacy committee hamper the funding? If the FEC is housed in a host agency how will the host agency be affected? These issues must receive careful scrutiny. A successful advocacy committee that chooses an activist path will need to possess a sophisticated sense of how to work within the political system, and needs to continually see itself and its activities as a part of the FEC and subject to its Coordinating Committee and to the host agency's Board of Trustees.

5. *Professionally-led groups*

The place of professionally-led groups needs to be viewed as clearly subordinate to the mutual-aid network which evolves from family to family activities. In our view too, they constitute a component in the design to be developed at a later stage in the process, and as a response to requests from families. Finally, the focus of such groups should be a form of social treatment. The rationale for employing professionals to run such groups is that it is crucial to supply leadership which has a sophisticated understanding and disciplined approach which comes from professional education.

In truth, we do not think that professionally-led groups are crucial to the design. They constitute a considerable outlay of staff time and money, as do all forms of treatment. It may be that an agency interested in replicating the FEC can stop short of including professionally-led groups, and instead take on an active information and referral service to help families who request counseling or therapy to find such resources in the community.

However, where it is feasible for an agency to include professionally-led groups, we think they can make an important contribution, if there is clarity about the composition, structure, and the purpose of such groups. We advise that the groups need to be homogeneous from the standpoint of all members experiencing the same common fate, because this makes for cohesion—a crucial property of the group. Composing separate groups for siblings, for mothers, and for fathers and grandparents, would be in keeping with this idea. Structure, or the way a group organizes itself to do its work, needs also to be considered. In contrast to the more informal arrangements characterizing the self-help groups in other parts of the FEC design, the professionally-led groups are best struc-

tured as closed-ended, and time-circumscribed. There is the expectation that members commit themselves to attend regularly and at some point in the group's life no additional members may join. Such a structure will enhance the level of trust which will develop and encourage the productive use of self-disclosure. Finally, as purpose is at the core of useful work in groups, thought and care has to be given by the agency to the "contracting process" between the group leader and the group members. By means of negotiation in which members express their needs and wishes for the group, and the leader makes a statement concerning the FEC's idea of purpose, an agreement is reached. This confluence gives direction to the subsequent work of the group. In this regard, it is to be expected that the content issues which members choose to focus on differ according to the common fate members are experiencing, e.g. siblings might talk about the problems of protecting possessions, mothers might talk about disappointment and hurt and fears for the future, and fathers might talk about feelings of embarrassment and outlets for coping with family troubles. However, though the issues may differ because the compositions of the groups are different, there is a purpose in common for all these professionally-led groups. The FEC needs to be clear that they are to be structured as discussion groups focused on the expression of feelings and ideas surrounding the developmentally disabled child and other family members. It is through such expressions and the accompanying empathic responses from others in the group that emotional support and problem-solving efforts may be achieved.

In summary, the inclusion of professionally-led groups in the design makes the FEC a more complex model of service. It includes elements of the old community Settlement House as well as professional counseling services, the self-help movement, mutual aid, with the families and professionals tied (in sometimes unclear ways) to the mix.

Alerts

In addition to the increased opportunities the FEC affords families to be involved with each other, it does also present new sets of questions particularly pertinent to professionally-led groups. For example, will increased interaction amongst parents and increased social networking interfere or enhance the extent to which parents disclose personal material in a group focused on social treatment? To what extent do the varied opportunities for parents to assume leadership roles with other parents result in ego satisfaction and increased feelings of competence? Or does this approach sometimes play into avoidance patterns and denial mechanisms which interfere with professional therapies?

We found that the FEC creates a system with programs that enhance natural opportunities for multiple and varied relationships with peers and professionals. In this context family and self-exploration is encouraged and the potential for growth and change is enhanced. The FEC creates an adaptive rather than a maladaptive community system; one which evokes health and strength. An ambience is established in which individual and family behavior changes as a result of supportive and personal social interactions. The FEC is a cost-effective prevention and service model. Its expanded consumer participation serves to improve the quality of the program itself.

VI. Administrative Considerations

A1. *Outreach to professionals*

Linkages between new programs and potential referral sources, as well as dissemination of information, are critical components of outreach efforts. Implementing new strategies calls for clarity of purpose. Outreach procedures as well as determination, time and energy on the part of the "missionaries" is required. In this respect, introduction of the FEC has some advantage because its basic tenets are beginning to achieve some professional acceptance. Bringing about program changes, however, calls for cooperation and activism from professionals, and not simply tacit approval. If we are to achieve this, the outreach team must be sensitive to the perceptions, needs and ideological biases of the professionals contacted. Needless to say there will be differences among the disciplines (educators, mental health providers) among settings (schools, agencies and hospitals) that are influenced by their orientations. Outreach efforts need to include an understanding of these factors and the behavioral patterns of the targeted audience in order to achieve support of this new program.

Efforts are sometimes impeded by prevailing "popular" attitudes. Public schools may have tendencies to exclude parents and biases which create obstacles to collaborations. Despite consensus on the value of shared responsibility, school personnel are often mistrustful of parents and their capabilities and sometimes alienate and inadvertently demean them. Mental health centers and their staffs still alienate parents because of their inclination to identify them as patients and suspect them of resistance or neglect when this designation is refused. In summary, this issue pointedly was addressed by Blatt (1978) who said, "There have hardly ever been partnerships between parents and professionals, and although the professionals are not entirely at fault, you know as well as I do that we could have done more to make those relationships better. Who can say why we didn't try harder to make it work?...I think that close to main reasons is (sic) the idea we have that professionals and parents are too different to develop genuine collaborations, that we know so much and they know so little, that we are ever so much better. I think that many professionals have the idea that we can't possibly have the clients' nasty problems. The disease of professionals is that we believe we are too good for the illnesses and problems with which we are required to deal. The disease of consumers is that they believe us, that they refuse to remember that people are people, that all are in need of something and someone."

Printed informational material for distribution is a necessity and can be mailed directly to agencies and individual professionals or handed out at conferences and meetings. Messages can be tailored for periodicals, newsletters and journals which have their own audiences and purposes.

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A2. *Outreach to consumers*

Initial outreach relied upon both personal contacts and mass media communication. In other words all the usual informational media sources were contacted: the press, radio, and TV with direct mailings, public service announcements, newsletters and press releases. These "marketing" activities targeted both parent organizations and key professionals in the special education and mental health sector who were in a position to inform potential consumers of this new service. The FEC used the media to inform the consumer and the public of its presence. A meeting for key professionals and parents in organizations with a referral potential was used to introduce the project. This was well attended and helped create a highly visible, easily accessed regional point of entry to services for families. All these efforts brought in some families but word of mouth and personal invitations were more effective.

Materials and presentations introduced the FEC concepts and the opportunity to participate in a mutual-aid network. Outreach activities highlighted the Sunday afternoon and afterschool programs which include recreational, spectator and social activities for all and/or parts of the family. They are powerful magnets because they provide natural respite for each member and ease from parenting responsibilities that most families take for granted.

At first we thought that interest in the networking would suffice to attract families. We soon learned otherwise. Although parents need other parents, they resist membership in this kind of special group. Specific attractive inducements were necessary if parents were to overcome their strong initial reluctance to membership in an organization which might only "further stigmatize their family."

The family fight against "shame" could prevent parents from joining others with similar difficulties. Before parents would begin to use the FEC in numbers, personal outreach on the part of convinced parents was necessary. The major inducements are:

- Leadership cadre of competent parents
- Support groups for well siblings
- Out of home childcare opportunities
- Special events of interest to the entire family

Parents responded to the afterschool offerings for their family and children with both interest, hope and concern. On the one hand it met their need for relief from the burdens of childcare and offered specific help with the painful questions of their well child. The program also

recognized the needs of all the children for expanded social horizons. Parents understood, too, that siblings needed to know more, but they were also afraid that their child might be exposed to unacceptable behavior and ideas. They thought they might share embarrassing family secrets. Perhaps the program leader's suggestions would be incompatible with their family values. Parents know they want their sibling to grow up loving and carrying some responsibility for the handicapped child. Perhaps the group experience would make things worse. Despite these concerns parents took the risk and enrolled their children.

With time, parents who came at first as escorts and onlookers remained to join themselves. There were some parents who used childcare for respite and left the building; more often parents stayed to seek out other parents. Each family who joined was encouraged to bring another. In this way we gradually increased our membership.

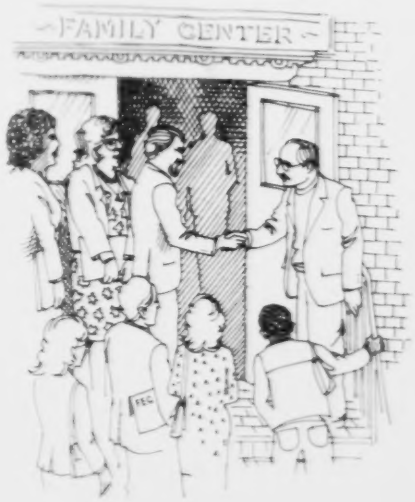
B. *Staffing*

The FEC requires a basic annual budget, but can be highly cost effective with contributions of time from volunteer parents, space from a host agency, childcare from volunteers, and "benefit" performances from local talents. Since a volunteer coordinator may not be readily found, a budget to cover a paid coordinator, part-time group leaders, a secretary and the cost of telephone, printing and office supplies would supply the basics.

Enthusiastic, well motivated and semi-skilled staff, ready to work for a reasonable fee, can be found in local universities, in special education, psychology, social work and nursing programs. Orientation, training and supervision from the coordinator will elevate and maintain their performance.

Volunteer support poses some problems. As a growing number of homemakers enter the work force this traditional pool of nurturing mature help has been shrinking. There is a need to tap new sources. We have attracted retired persons, high school and college students and members of service clubs. These groups seem more amenable to volunteer work with the developmentally disabled. Out of fear or ignorance other community members are sometimes reluctant to work with this population. This is an issue that must be addressed.

Local service clubs and funds, as well as parent organizations, are likely to be responsive to requests for financial support and can provide an enthusiastic supportive community constituency.



VII. Supplementary Reading

Blatt, B. (1978) Introduction: The Threatened Planet. A. P. Turnbull & H. R. Turnbull (Eds.), *Parents Speak Out: Views from the Other Side of the Two-way Mirror*. Merrill, Columbus, Ohio.

Katz, Alfred and Bender, Eugene (1976) The Strength in Us. New Viewpoints. New York.

Lieberman, M. and Borman, L. (1979) Self-help Groups for Coping with Crisis. Jossey Bass, San Francisco.

Riessman, Frank (1965) The "Helper" Therapy Principle. Social Work, vol. 10, pp. 27-32.

Rothman, Jack (1983) Marketing Human Service Innovations. Sage Publications, Beverly Hills.

Silverman, Phyllis R. (1980) Mutual Help Groups: Organization and Development. Sage Publications, Beverly Hills.

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Martin Seitz, ACSW, is an Associate Professor at Adelphi University School of Social Work and a trainer and consultant on group methods. He has had extensive experience with children with special needs and their families as both a social worker and an executive director. He has published in professional journals and coauthored with Dr. Bert Kaplan *The Practical Guide to Foster Family Care*. Mr. Seitz is the recipient of the Smadbeck Foundation Award and was selected as "Social Worker of the Year" in 1965.

"...It is very nicely done. The rationale is well thought out and presented, and your description of the impact of a less than perfect child on the family system is sensitive and apropos. I love the way you have interspersed the "Alerts."

—Marilyn M. Segal, Ph.D.
Director, The Family Center of Nova University